

NEW FREEDOM INITIATIVE

Demonstrations Proposed in the President's FFY 2003 Budget

*The material contained here is preliminary and is intended only for the purpose of
stimulating feedback.*

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NEW FREEDOM INITIATIVE

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I. A. Demonstration of Respite Services for Children

HHS Report Item Number III.B.2

Background and Overview

I. Background

Caregivers of children with a disability face the same barriers and challenges as those faced by caregivers of adults. It can be highly stressful and is a major contributing factor to caregiver illness, marital discord and divorce, and institutionalization of individuals with a disability. Many family members report that they are unable to leave their family member with a disability with another relative or sitter, that some day care centers will not accept people with disabilities, and that it is not safe for the individual with the disability to be left at home alone. Occasional periods of respite care can significantly reduce stress in the family and enhance the ability to keep the family member at home and in the community.

However, special issues pertain to the question of developing a national program under Medicaid for support of caregivers of children. One concern is that under Medicaid's Early and Periodic Screening, Diagnostic, and Treatment Program (EPSDT) an optional Medicaid service, by law, is mandatory upon States with regard to children determined to require such services. It is not the intention of this HHS initiative to create mandates for States that might require substantial State matching funds. A demonstration program will permit CMS and States to obtain more specific cost and utilization data, evaluate the effects of improved caregiver support on the well-being of families and on possible savings in other programs (such as reduced out-of- home placements).

II. Overview of Demonstration

CMS will seek authorization and funding from Congress to implement an evaluated, 10-year demonstration to provide essential relief to caregivers of children who have a substantial disability. The demonstration would be limited by the total national number of enrollees and would allow States to establish flexible respite services for such caregivers, tailored to the needs of individual families. The demonstration would also include an evaluation of the possible effects of including supervision under personal assistance services. In this flexible "Medicaid-like" demonstration States would be required to:

- A. Provide State match at the same rate as Medicaid and closely coordinate such demonstration services with services available under the State Medicaid plan;
- B. Maintain fiscal effort for services to children with disabilities.

Draft Specifications

Children's Respite Demonstration

I. Authority

The Secretary of the Department of Health and Human Services has the responsibility for administering this demonstration.

II. Length of the Demonstration

The demonstration project may be commenced any time after September 30, 2002 and shall be conducted for ten-years from the date of implementation.

III. State Application

A State may make an application to participate in this demonstration to provide respite services under Medicaid to caregivers of children who meet the SSI level of disability provided that the State:

- A. Specifies a numerical limit on the number of individuals who would be enrolled in the demonstration;
- B. Provides State match at the same rate as Medicaid for both providing and administering the respite service under this demonstration;
- C. Defines the service area of the demonstration which may include a sub-State demonstration;
- D. Provides respite services within the limits established by the Secretary;
- E. Agrees to closely coordinate such demonstration services with services available under the State Medicaid plan;
- F. Meets the maintenance of effort requirement described below; and
- G. Agrees to conduct an independent evaluation of the demonstration as described below.

IV. Eligibility for the Demonstration

Under this demonstration, the individuals who meet all of the following criteria would be eligible for respite services:

- A. Individuals who are eligible to receive benefits under the Supplemental Security Income (SSI) program. These individuals do not have to actually be receiving SSI benefits.
- B. Individuals who are Medicaid eligible in that State.
- C. Individuals who meet the age criteria established by the State. The State must choose one of the following age groups.
 - 1. Age 16 and under;
 - 2. Under age 18; or
 - 3. Age 21 and under.

V. Definition of Respite

The State may specify the number of hours and/or number of days allowed under the benefit subject to the approval of and within the limits established by the Secretary.

VI. Waivers of requirements

With respect to carrying out this demonstration project, the Secretary may waive the following requirements of the Social Security Act at the request of the State:

- A. Section 1902 (a)(1) relating to statewideness;
- B. Section 1902 (a)(10)(B) relating to comparability of services;
- C. Section 1902 (a) (27) relating to establishing provider agreements.
- D. EPSDT if the demonstration is constructed under Medicaid.

VII. Terms And Conditions Of Demonstration Projects

Any approved demonstration project must meet the following conditions:

A. Maintenance Of State Effort-

- 1. **Financial:** Federal funds paid to a State pursuant to this demonstration must be used to supplement, but not supplant, the level of State funds and Federal funds expended for children with disabilities for respite programs in effect for such individuals at the time the demonstration project is approved, or other such time close to the approval date that is approved by the Secretary for which reasonably accurate data are available.
- 2. **Programmatic:** In addition, the State agrees to continue throughout the demonstration the level of respite services provided to children with disabilities on both an individual and aggregate basis in effect for such individuals at the time the demonstration project is approved.

B. Quality Assurance and Independent Evaluation-

- 1. The Secretary shall conduct an evaluation and take reasonable steps to assure quality in the demonstration. Of the funds appropriated in Section VIII below, the Secretary may use up to \$1,700,000 for the period of FY2003 through FY2007, and \$2,500,000 for the period of FY2008 through FY2012 for the purpose of assuring quality respite services and conducting a national evaluation of the demonstration. For purposes of conducting the evaluation and assuring quality, Section 1905(b) regarding State match shall not apply.
- 2. All participating States must agree to meet the requirements of an independent evaluation of the project as determined necessary by the Secretary including the collection of specific cost and utilization data to determine the effect of improved caregiver support on the well-being of families and on possible savings in other programs.

VIII. Limitations On Federal Funding

A. Appropriations:

1. The following amounts are appropriated to carry out this section
\$1,017,000 for the fiscal year 2003
\$2,366,000 for the fiscal year 2004
\$4,023,000 for the fiscal year 2005
\$6,391,000 for the fiscal year 2006
\$9,606,000 for the fiscal year 2007
\$11,398,000 for the fiscal year 2008
\$11,943,000 for the fiscal year 2009
\$12,515,000 for the fiscal year 2010
\$13,116,000 for the fiscal year 2011
\$13,746,000 for the fiscal year 2012
2. This constitutes budget authority in advance of appropriations Acts and represents the obligation of the Federal Government to provide for the payment of the amounts appropriated above.

B. Funds Allocated To States The Secretary shall allocate funds to States based on their applications and the availability of funds. Funds allocated to a State under a grant made for a fiscal year shall remain available until expended.

C. Funds Not Allocated To States- Funds not allocated to States in the fiscal year for which they are appropriated shall remain available in succeeding fiscal years for allocation by the Secretary.

D. Payments To States-

1. Payment for Services: The Secretary shall pay to each State with a demonstration project approved under this section from its allocation, an amount for each quarter equal to the Federal medical assistance percentage (as defined in section 1905(b) of the Social Security Act (42 U.S.C. 1395d(b)) of expenditures in the quarter for respite services provided under this demonstration.

2. Infrastructure Grants: Out of the funds appropriated above, the Secretary may make grants to States not to exceed \$300,000 each year for fiscal years 2003 through 2007 to develop State infrastructure supporting the demonstration. For purposes of the infrastructure grant and any evaluation activities, Section 1905(b) regarding State match shall not apply.

I. B. Demonstration of Respite Services for Adults

HHS Report Item Number III.B.1

Background and Overview

I. Background

Respite care – temporary care that offers support to family caregivers – is the service most often requested by families in an effort to keep their family member with a disability at home. Caring for a family member with a disability is highly stressful. Unrelieved caregiver burden is a major contributing factor to caregiver illness, marital discord and divorce, and institutionalization of individuals with a disability. Many family members report that they are unable to leave their family member with a disability with another relative or sitter, that some day care centers will not accept people with disabilities, and that it is not safe for the individual with the disability to be left at home alone. Occasional periods of respite care can significantly reduce stress in the family and enhance the ability to keep the family member at home and in the community.

Respite care can take many forms. Care may be provided in the family home, allowing the care-taking family member to get away for a few hours, or in the respite provider's home. It can also be provided in day programs and senior centers. In some cases, group homes or other facilities may provide overnight or weekend care.

Medicaid requirements currently limit respite care to home and community-based waiver programs. Such programs are limited to people who already require institutional level of care, often have long wait lists, and are best suited for individuals who require a full package of services rather than a targeted service such as respite. To the extent a Medicaid respite service extends the capacity of families to keep their loved ones at home and delay or prevent the use of more expensive forms of care, the service could result in some offsetting cost savings for Medicaid and Medicare.

II. Overview

HHS will seek authorization and funding from Congress to conduct a ten year national demonstration that would allow States to provide respite care (temporary care that offers support to family caregivers) for adults as a fixed budget demonstration. The State option would provide essential relief to unpaid caregivers (including, for example, persons providing continuous care and supervision to an individual with Alzheimer's or mental illness) within specified federal limits. States could establish more restrictive limits, utilization controls. States would be required to provide State match at a ratio equivalent to the ratio in Medicaid. States would be required to maintain fiscal effort for caregiver support.

In addition to the provision of a needed service, the demonstration would permit CMS and States to assess and gain valuable experience regarding the impact and management of a respite service operating under a Medicaid auspice; impact issues relate to target group uptake, rates, utilization, costs, types and location of effective respite; impact on caregivers (continuity, stress, health, satisfaction, and relationships); impact on the individual for whom care is provided, and the impact on cost and utilization of Medicaid services (e.g., home health and nursing facility).

III. Supporting Research

There are about 7 million caregivers nationwide (National Long-Term Care Survey)

An estimated 1.6 million elders with severe long term disabilities (3 or more ADL dependencies or severe cognitive impairment) are able to live in the community in their own or a relative's home.

The availability of support from family and friends is a significant factor in whether individuals with chronic illness or disability are able to avoid costly institutionalization.

Draft Specifications

Adult Respite Demonstration

I. Authority

The Secretary of the Department of Health and Human Services has the responsibility for administering this demonstration.

II. Length of the Demonstration

The demonstration project may be commenced any time after September 30, 2002 and shall be conducted for ten years from the date of implementation.

III. State Application

A State may make an application to participate in this demonstration to provide respite services under Medicaid to caregivers of adults with disabilities who are Medicaid-eligible provided that the State:

- A. Specifies a methodology to test the effect on enrollment and utilization that would likely occur if respite for adults were a Medicaid service under the State plan;
- B. Defines what, if any, numerical or budgetary limits would be in effect subject to the approval and within the parameters established by the Secretary;
- C. Provides State match at the same rate as Medicaid for both providing and administering the respite service under this demonstration;
- D. Defines the service area of the demonstration which may include a sub-State demonstration;
- E. Agrees to closely coordinate such demonstration services with services available under the State Medicaid plan and other State-administered programs that support family caregivers including the National Family Caregiver Support Program;
- F. Meets the maintenance of effort requirement described below; and
- G. Agrees to conduct an independent evaluation of the demonstration as described below.

IV. Eligibility for the Demonstration

Under this demonstration, the individuals who meet all of the following criteria would be eligible for respite services:

1. Individuals who are Medicaid eligible in that State, and
2. Individuals who demonstrate a need for long-term supports and services through a State assessment subject to the approval and parameters as established by the Secretary, and
3. The individual is age 18 or older. At the States' option, the age criteria may be set at 22 and over, and
4. Meets at least one of the following level of care requirements:

A. is unable to perform at least one activity of daily living without substantial human assistance, including verbal reminding, physical cueing or supervision; or

B. due to a cognitive or other mental impairment requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.

V. Definition of Respite

The State may specify the number of hours and/or number of days allowed under the benefit subject to the approval and within the parameters established by the Secretary.

VI. Waivers of requirements

With respect to carrying out this demonstration project, the Secretary may waive the following requirements of the Social Security Act:

- A. Section 1902 (a)(1) relating to statewideness;
- B. Section 1902 (a)(10)(B) relating to comparability of services provided that a waiver of this requirement would not impede the modeling of respite as a Medicaid State Plan service;
- C. Section 1902 (a)(27) relating to establishing provider agreements.

VII. Terms And Conditions Of Demonstration Projects

Any approved demonstration project must meet the following conditions:

A. Maintenance Of State Effort-

1. **Financial:** Federal funds paid to a State pursuant to this demonstration must be used to supplement, but not supplant, the level of State funds and Federal funds expended for individuals with disabilities for respite programs in effect for such individuals at the time the demonstration project is approved.
2. **Programmatic:** In addition, the State agrees to continue throughout the demonstration the level of respite services provided to individuals with disabilities on both an individual and aggregate basis in effect for such individuals at the time the demonstration project is approved.

B. Quality Assurance and Independent Evaluation-

1. Of the funds appropriated in Section VIII below, the Secretary may use up to 5% of funds, not to exceed \$1.0 million in a 12 month period, for the purpose of assuring quality of respite services and conducting a national evaluation of the demonstration. For purposes of conducting the evaluation and assuring quality, Section 1905(b) regarding State match shall not apply
2. The State agrees to meet the requirements of an independent evaluation of the project as determined necessary by the Secretary to evaluate the results of the project such as the impact and management of a respite service operating under a Medicaid auspice; impact issues relating to target group uptake, rates, utilization, costs, types and locations of effective respite; impact on caregivers (continuity, stress, health, satisfaction, and relationships); impact on the individual for whom care is provided; and the impact on cost and utilization of Medicaid and Medicare services (e.g., home health and nursing facility).

VIII. Limitations On Federal Funding-

A. Appropriations:

1. The following amounts are appropriated to carry out this section
 - \$ 6,750,000 for the fiscal year 2003
 - \$ 15,030,000 for the fiscal year 2004
 - \$ 24,970,000 for the fiscal year 2005
 - \$ 36,690,000 for the fiscal year 2006
 - \$ 50,320,000 for the fiscal year 2007
 - \$ 57,110,000 for the fiscal year 2008
 - \$ 59,788,000 for the fiscal year 2009
 - \$ 62,911,000 for the fiscal year 2010
 - \$ 66,034,000 for the fiscal year 2011
 - \$ 69,157,000 for the fiscal year 2012
2. This constitutes budget authority in advance of appropriations Acts and represents the obligation of the Federal Government to provide for the payment of the amounts appropriated above.

B. Funds Allocated To States: The Secretary shall allocate funds to States based on their applications and the availability of funds. Funds allocated to a State under a grant made for a fiscal year shall remain available until expended.

C. Funds Not Allocated To States: Funds not allocated to States in the fiscal year for which they are appropriated shall remain available in succeeding fiscal years for allocation by the Secretary using the allocation formula established under this section.

D. Payments To States:

- 1. Payments for Services:** The Secretary shall pay to each State with a demonstration project approved under this section from its allocation an amount for each quarter equal to the Federal medical assistance percentage (as defined in section 1905(b) of the Social Security Act (42 U.S.C. 1395d(b)) of expenditures in the quarter for respite services provided under this demonstration.
- 2. Infrastructure Grants:** Out of the funds appropriated above, the Secretary may make grants to States not to exceed 5% funds or \$500,000, whichever is less, for the purpose of developing State infrastructure to support the demonstration. For purposes of the infrastructure grants, Section 1905(b) regarding State match shall not apply.

I. C. Demonstration of Community-Based Alternatives to Psychiatric Residential Treatment Facilities for Children

HHS Report Item Number I.A.8

Background and Overview

I. Background

Medicaid provides inpatient psychiatric services for children under age 21 in hospitals. The statute also extends these Medicaid benefits to children in psychiatric residential treatment facilities. Over the last decade, psychiatric residential treatment facilities have become the primary provider for children with serious emotional disturbance requiring an institutional level of care. However, since they are not recognized as hospitals, they do not qualify as institutions against which States may measure HCBS (1915(c)) waiver costs and States have been unable to use the 1915(c) waiver authority to provide community-based alternatives to care that would keep the children in their homes and with their families.

II. Overview

CMS seeks the statutory authority to run a 10-year demonstration of community-based alternatives to Medicaid funded psychiatric residential treatment facilities for children under age 21. Psychiatric residential treatment facilities are residential treatment facilities that provide the Medicaid inpatient psychiatric services for children under 21 (psych under 21) benefit.

This demonstration is intended to mimic the 1915(c) statute in that States are essentially being given the opportunity to establish a home and community-based waiver as an alternative to care in a psychiatric residential treatment facility. The differences between this demonstration and the 1915(c) waiver authority are the following: the demonstration will last for 10 years and will not require renewal every 3 or 5 years; the demonstration will be evaluated; the demonstration is fixed cost and will have a national enrollment target; the demonstration will have a maintenance of effort requirement; and the demonstration will have specific participation requirements involving coordination and adequacy of State plan services, and quality improvement and assurance.

Draft Specifications

Community-Based Alternatives to PRTFs

I. Authority

The Secretary of the Department of Health and Human Services shall undertake a 10-year demonstration. The Secretary will retain the authority to terminate any State's participation at any time if participants' health and well-being is found to be jeopardized. This demonstration will be set up as a separate section of Title XIX of the Social Security Act with a sunset date of 10 years from enactment.

II. State participation

States will enroll in the demonstration by submitting applications to CMS for approval. States will be required to specify a minimum and maximum enrollment. States will be required as a term and condition of the demonstration to cover at least the minimum number of individuals and will not be permitted to enroll more than the maximum number of individuals specified by the State. States will also have to specify a service package using both waiver and State plan services that is both adequate to meet the needs of the children being served and at least equal to services provided to categorically needy eligibility groups. As with 1915(c) waivers, both comparability and statewideness will be waived for purposes of this demonstration at the option of the State. States will be expected to submit cost data using the same cost-effectiveness test that they currently use for other 1915(c) waivers.

III. Quality Assurance

Participating States shall be required to maintain a quality assurance program that provides for the ongoing health and well-being of each participant. Quality assurance systems must be approved as part of the application process to CMS.

IV. Eligible Participants

States may enroll children into this demonstration who are Medicaid eligible, meet institutional level of care criteria and would otherwise be served in psychiatric residential treatment facilities. States may opt to apply 1915(c) waiver financial eligibility standards.

V. Funding in advance of appropriations

The following amounts are appropriated to carry out this section:
(The funding for this demonstration is complex because the demonstration has costs in each year and Medicaid achieves some savings from it in each year.)

<u>Cost of demo</u>	<u>Savings to Medicaid baseline</u>
FY 03 \$ 22.3million	\$ 23

FY 04 \$ 44.3	\$ 46
FY 05 \$ 57.3	\$ 48
FY 06 \$ 70.3	\$ 49
FY 07 \$ 70.3	\$ 49
FY 08 \$ 70.3	\$ 49
FY 09 \$ 70.3	\$ 49
FY 10 \$ 70.3	\$ 49
FY 11 \$ 70.3	\$ 49
FY 12 \$ 70.3	\$ 49

Of the funds made available under this demonstration, \$1.3 million per year will be made available to HHS for quality assurance and evaluation activities.

VI. Funds not allocated to States

Funds not allocated to States in the fiscal year for which they are appropriated shall remain available in succeeding fiscal years for allocation by the Secretary.

VII. Payments to States

The Secretary shall pay each State with a demonstration project an amount for each quarter equal to the Federal medical assistance percentage (as defined in Section 1905(b) of the Social Security Act (42 U.S.C. 1395d(b)) of expenditures in the quarter for this demonstration.

VIII. Maintenance of effort

Participating States must maintain FY 2002 levels of spending or greater on home and community-based services for children with serious emotional disturbance provided through both Medicaid and State-only programs for the duration of the demonstration program.

IX. Independent Evaluation

The Secretary will provide for an independent evaluation of the project to evaluate specific cost and utilization data and to determine the effectiveness of community placements for children with serious emotional disturbance. States participating in the demonstration project must agree to comply with the requirements of the evaluation.

I. D. Demonstration of Methods to Recruit and Retain More Direct Service Workers

HHS Report Item Number I.C.1

Background and Overview

I. Background

One of the barriers to the expanded availability of community-based long term care alternatives is a tremendous shortage of direct service workers who serve as personal care attendants. These jobs are traditionally low paying jobs that are without benefits or advancement opportunities. The absence of health insurance coverage, and other benefits such as education and day care vouchers for direct care workers is one of the factors that limits recruitment. These limits also decrease the viability of introducing the occupation to Temporary Assistance for Needy Families (TANF) recipients seeking employment and reduced dependency on public programs. Ultimately these limits reduce the ability of people with disabilities to live in the community.

II. Overview

In order to gather better research on recruitment and retention strategies, CMS, together with a limited number of volunteer States, will run a national demonstration designed to address workforce shortage issues. The demonstration will test the extent to which workforce shortages and instabilities might be addressed through (a) better coordination with the TANF program and (b) the availability of vouchers for worker health insurance or for tuition and day care credits. Participating States would be expected to develop options for workers to purchase affordable group health coverage through the State health insurance system or similar organized insurance group.

Draft Specifications Direct Service Worker Demonstration

The funding for this demonstration is under the CMS research and demonstration budget. However, since this demonstration will permit States to partner with other benefit programs such as the State Employees' Health Benefit Plan to extend benefits to workers and will then require measurement of the effect on workforce recruitment and retention, the demonstration will not be effective unless it can be conducted over an extended time period. It is important for States to have commitments up front for funding even though the money will be spent over several years. States need to have firm funding commitments in order to make the necessary partnerships with health plans, and create voucher programs for child care and education. Without a 48 month time period on such

a program, States will not be able to create the necessary partnerships and enroll direct workers with sufficient time to measure cause and effect.

Additionally, the program design for this demonstration is envisioned to include a two year award process under which \$6 million will be distributed to grantees in year one followed by \$3 million in year two. Therefore, deviation from standard research and demonstration authority is necessary so that the States and the Federal Government may carry the appropriated funding forward for 48 months.